

## HIV

# Sex and relationships for HIV positive women since HAART: a quantitative study

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**Objective:** To investigate current levels of sexual activity, enjoyment, condom use, and other factors affecting sexual behaviour in a sample of women living with HIV.

**Method:** Participants were self selected. A cross sectional design using semi-structured questionnaires was employed. 82 HIV positive women completed questionnaires asking about demographics, relationships, sexual behaviour, and safer sex practices. The Hospital Anxiety and Depression Scale (HADS) and Golombok-Rust Inventory of Sexual Satisfaction (GRISS) were administered.

**Results:** 28% of women had had no sexual partners since diagnosis. Mean time diagnosed was 69 months, range 4–191 months. Time since diagnosis was not associated with having had a sexual partner. 59% of women had a current sexual partner, half reporting intercourse in the past month. Infrequent sex (84%), avoidance (84%), non-communication (69%), and dysfunction (60%) were among the most prevalent sexual difficulties. Endorsement of HIV impaired sexual enjoyment was associated with reduced sexual frequency ( $p=0.006$ ) and sexual dysfunction ( $p=0.042$ ). Sexual dissatisfaction was associated with infrequency of sex ( $p=0.037$ ), avoidance ( $p=0.02$ ), and non-communication ( $p=0.032$ ). Clinically significant levels of anxiety and depression were reported in 60% and 38% of cases, respectively. Depression was associated with avoidance of sex and higher total GRISS scores ( $p=0.006$  and  $p=0.042$ ). 60% of respondents stated that they "always" used condoms; a trend was observed between reduced condom use and higher levels of depression and anxiety ( $p=0.09$  and  $p=0.06$ , respectively).

**Conclusion:** Sexual difficulties, including abstinence, were prevalent in this sample indicating the potential for interventions addressing the psychosexual needs of HIV positive women and their partners.

There are few studies examining sexual and relationship difficulties among HIV positive women since the advent of antiretroviral medication although increased longevity may renew interest in this aspect of quality of life. Early studies in US samples suggest high rates of reduced sexual drive and frequency of sexual activity in women since HIV seroconversion,<sup>1,2</sup> with rates of persistent hypoactive sexual desire reported to be 60% in women with HIV infection.<sup>3</sup>

Other studies suggest a majority of HIV positive women remain sexually active.<sup>4,5</sup> Among a mixed Canadian sample of injecting drug users (IDU) and non-IDU of Haitian, African, and white background, 68% of women had been sexually active since diagnosis. Sexual activity since diagnosis and in the past month was associated with self reported CD4 count.<sup>4</sup> A recent US study of 101 HIV positive women reported that higher levels of sexual functioning were associated with fewer HIV related symptoms, better mental health, and never having used injecting drugs.<sup>5</sup>

There is mixed evidence that decreased sexual interest may be associated with antiretroviral medication, particularly protease inhibitors (PI), in both men and women.<sup>6</sup> The same study also found that symptomatic HIV disease and older age were also associated with decreased sexual interest.<sup>6</sup> In a recent European study, the same authors evaluated sexual dysfunction in HIV positive women using the female sexual function index and concluded that psychological factors (depression, irritability, anxiety) and the HIV diagnosis itself were more likely to be the main drivers of sexual difficulties and not necessarily the commencement of antiretroviral treatment.<sup>7</sup>

There is little published work on the sexual functioning of seropositive women living in England. The ethnic and cultural backgrounds and route of acquisition of HIV for women in the US samples differs from those of women in the

United Kingdom, making it difficult to generalise findings. In the United Kingdom, 61% of the estimated 10 052 women known to be infected are black African, having acquired HIV via heterosexual sex, in Africa.<sup>8</sup> IDU accounts for only 8% of infections in women.<sup>9</sup> The aims of this study were (1) to investigate current levels of sexual activity in a sample of HIV positive women in the United Kingdom; (2) to examine safe sex practices, and (3) to investigate associations between psychological variables, disease variables, sexual functioning, and condom use.

## METHOD

### Design

The study employed a cross sectional design using quantitative and qualitative methods to investigate sexual behaviour and relationships in a sample of women living with HIV. The quantitative data only are presented here.

### Participants

Women were recruited from HIV clinics on two hospital sites of an inner London NHS Trust and from voluntary organisations. For clinic attendees, the investigators compiled a list of all women registered on the HIV clinic databases on both sites. For voluntary organisations, two investigators (AK and SL) attended two evening meetings, one a women's support group and one a mixed sex group for refugees and people seeking asylum. An advertisement was placed in *Positively Women* magazine, a monthly publication distributed throughout the United Kingdom.

**Abbreviations:** GRISS, Golombok-Rust Inventory of Sexual Satisfaction; HADS, Hospital Anxiety and Depression Scale; IDU, injecting drug users; PI, protease inhibitors

**Table 1** CD4 count and viral loads (n = 81)

CD4 count ( $\times 10^6/l$ )	No	%	Viral load (/ml)	No	%
<100	5	6	Undetectable	30	37
101–200	10	12	<10 000	12	14
201–300	16	20	10 000–100 000	3	4
301–500	27	34	>100 000	5	6
> 500	10	12	"Don't know"	32	39
"Don't know"	13	16	–	–	–

### Procedure

Hospital questionnaire distribution occurred on a weekly basis. Investigators placed a questionnaire, information sheet, and consent form in the patient's medical notes before the consultation. At the voluntary organisations, attendees were given a brief explanation of the study and invited to participate by completing a questionnaire. In response to the *Positively Women* advertisement, a group from Manchester expressed interest and 25 questionnaires were sent for distribution to their members. Questionnaire distribution took place between January and December 2002.

The East London and City Health Authority research ethics committee approved this study.

### Measures

#### Semi-structured questionnaire

A semi-structured questionnaire was developed from themes that emerged in earlier interviews with 20 clinic attendees. Information on the following areas was gathered: demographics, social support, health and risk issues, treatment, family issues, sexual history and behaviour, safe sex practices, history of abuse, and mental health.

#### The Hospital Anxiety and Depression Scale (HADS)<sup>10</sup>

The HADS is a self report, widely used measure of anxiety and depression comprising seven items in each of the depression and anxiety subscales. Cut-off scores determine severity of depression and anxiety. Within medical samples, the HADS has demonstrated acceptable internal consistency, concurrent and construct validity.

#### Golombok-Rust Inventory of Sexual Satisfaction (GRISS)<sup>11</sup>

The GRISS is a validated measure for individuals in heterosexual relationships, consisting of 28 self report items designed to assess the quality of relationships and sexual functioning. Separate scales exist for men and women. Seven subscales are derived from the 28 items: non-communication, infrequency, dissatisfaction, avoidance, non-sensuality, vaginismus, and anorgasmia. Cut-off scores indicating clinically significant levels of difficulty determine severity of

problem. The measure has demonstrated acceptable levels of reliability and validity.<sup>11</sup>

Data were analysed using Statistical Package for Social Sciences (SPSS) version 11.0.

## RESULTS

### Sample characteristics

Eighty two women completed questionnaires: 59 (72%) were recruited through HIV clinics and 23 (28%) through voluntary organisations. The mean age of participants was 37.9 years, range 20–64 years; 75% of the women identified themselves as "black African," with 6% identifying as "white UK," 6% "European," and 13% "other" (black Caribbean, black UK, Pakistan, Irish). Fifty two (63%) women were unemployed, 23 (28%) were employed, and seven (9%) were students. Over three quarters had attended college or university.

### HIV diagnosis and treatment

Mean time since HIV diagnosis was 68 months, range 4–191 months; 59% of the 80 women who responded to the questions about diagnosis and treatment were on antiretroviral therapy, mean time on therapy 33 months (range 3–95 months). Table 1 shows the CD4 and viral loads for women in the sample. 39% of women were unable to report their viral load.

### Past and current relationships

Women were asked about number of sexual partners since diagnosis. Of the 76 women who responded, 21 (28%) had not had any partners; 27 (36%) and 10 (13%) reported one and two partners, respectively; 12 (16%) had between three and five sexual partners and only six (8%) had more than five.

Forty eight (59%) of 81 women who responded reported having a regular male partner; and 25 (52%) had been sexually active in the past month. Mean length of relationship was 75 months (median 72 months, range 2–480 months). None of the women reported only having casual sexual partners; 38 (79%) women had disclosed their

**Table 2** Transformed GRISS subscale scores (n = 38)

Transformed GRISS subscale scores (n = 38)	Above cut off for clinically significant problem	Below cut off(non-case)
	No (%)	No (%)
Non-communication	25 (66)	13 (34)
Infrequency	32 (84)	6 (16)
Dissatisfaction	13 (34)	25 (66)
Avoidance	32 (84)	6 (16)
Non-sensuality	22 (58)	16 (42)
Vaginismus	23 (60)	15 (40)
Anorgasmia	9 (24)	29 (76)
Total score	22 (42)	16 (58)

**Table 3** Impact of HIV status on sexual enjoyment (n = 67)

Statement: "Being HIV positive ..."	Frequency	%
"... has made no real difference to my enjoyment of sex"	12	18
"... has slightly reduced my enjoyment of sex"	19	28
"... has moderately reduced my enjoyment of sex"	4	6
"... has greatly reduced my enjoyment of sex"	16	24
"... has made it impossible for me to have sex"	16	24

HIV status to their partner and 22 (46%) women had HIV positive partners.

Participants were asked to comment on their reasons for not having sex, if applicable. Difficulties relating to finding the "right partner" predominated but fear of disclosure, fear of infecting a partner, and refusal by partners to use condoms were also given. Some women cited loss of libido and attributed this to side effects of their antiretroviral therapy.

### Sexual satisfaction and functioning

Thirty eight (79%) of 48 women who were in a relationship completed the GRISS. Of these, 19 (50%) reported having had sexual intercourse in the last month. Ten incomplete questionnaires were not included in the analysis; of these six were from women reporting intercourse in the last month. Table 2 shows the numbers of women who obtained scores above the cut-off point indicating a clinically significant degree of difficulty in each of the problem areas.

### Impact of HIV on sexual enjoyment

Participants were asked to rate the extent to which being HIV positive had affected their enjoyment of sex, irrespective of whether they had a current partner. Sixty seven participants responded to this item and the results are shown in table 3. Sexual enjoyment was examined in relation to disease variables but no associations were found for either CD4 count or viral load.

### Condom use in current relationship

Forty three women responded when asked about condom use with their current male partner. Twenty six (60%) women stated that they always used a condom, while four (9%) and 11 (26%) women reported using condoms "usually" and "sometimes," respectively. Two women (5%) stated that they never used condoms. Table 4 shows the reasons given for using condoms.

Among reasons given for not using condoms, "partner refusal" was given by seven (16%) of the women, as was "we are both HIV positive." Three (7%) women stated that they did not use condoms because they wanted to become pregnant. Six (14%) respondents reported that condoms interfered with their partner's enjoyment of sex, while three (7%) women stated that condoms interfered with their own pleasure.

### Success at practising safe sex

When asked about success at practising safer sex, 51 women responded; 21 (41%) thought they had been "extremely

successful," 24 (47%) "moderately" to "very successful," three (6%) "quite a bit," and three (6%) "not at all successful." Twenty three (43%) women reported difficulties in practising safe sex in their relationships.

### Current levels of anxiety and depression

On the HADS depression subscale (n = 75), 16 (21%) women reported symptoms of mild depression and 13 (17%) reported symptoms that reflected moderate to severe levels of depression. On the HADS anxiety subscale (n = 73), 12 (16%) women reported mild anxiety, while 32 (44%) were experiencing moderate to severe anxiety.

### History of sexual and physical abuse

Of those who responded (n = 74), 30 (41%) women reported a history of sexual abuse; this involved vaginal penetration in 21 (70%) cases; 16 women (53%) reported abuse on more than one occasion. No current sexual abuse was reported. Of those who responded (n = 70), 24 (34%) women reported having experienced past physical abuse; of these, 17 (71%) had experienced it on more than one occasion and three (4%) reported current physical abuse, one from her husband and two from men associated with their landlords.

### Association between relationship status, HIV related variables, and psychological factors

$\chi^2$  tests revealed that time since diagnosis, current antiretroviral use, CD4, and viral load were not associated with relationship status. Current anxiety and depression and past history of sexual or physical abuse were not associated with being in a relationship. No association was found between psychological distress and history of abuse.

### Relationship between GRISS subscales

Relationships between GRISS subscale scores were examined using bivariate Pearson correlations. Table 5 shows where significant correlations were found between scores. All GRISS subscale scores were highly correlated ( $p < 0.01$ ) with the individual subscale scores, as one would expect.

### Association between GRISS subscales and changes in sexual enjoyment since HIV diagnosis

Enjoyment of sexual activity since receiving an HIV diagnosis was explored in relation to sexual satisfaction and difficulty, as measured by GRISS subscale scores. Using  $\chi^2$  tests, endorsement of HIV impairing sexual enjoyment was significantly associated with "infrequency" of intercourse

**Table 4** Endorsement of reasons for using condoms with regular partners (n = 43)

Reasons for using condoms	Frequency	%
To protect my partner from HIV	28	61
To protect myself against STIs	36	78
To protect my partner against STIs	20	43
To prevent pregnancy	23	50

**Table 5** Significant correlations between individual GRISS subscale scores (n = 38)

GRISS subscales	Non-communication	Dissatisfaction
Infrequency	0.318*	0.340**
Dissatisfaction	0.349**	–
Anorgasmia	0.408**	–
Avoidance	–	0.375**
Non-sensuality	–	0.318*

\*p=0.052 \*\*p&lt;0.05.

( $\chi^2 = 12.3$ , df = 3, p = 0.006) and “vaginismus” ( $\chi^2 = 8.2$ , df = 3, p = 0.042).

### Association between sexual satisfaction, psychological, and HIV related variables

GRISS subscale scores were examined in relation to levels of depression and anxiety as measured by the HADS. Using bivariate Pearson correlations, no significant associations were found between any aspect of sexual satisfaction and concurrent level of anxiety. Conversely, significant correlations were found between depression scores and the “avoidance” and “total” scores on the GRISS (p = 0.007 and p = 0.04, respectively). There was also a trend towards significance for “dissatisfaction” and “infrequency” (p = 0.061 and p = 0.081, respectively).

$\chi^2$  tests were used to examine the relation between GRISS subscales and history of sexual abuse. A significant association was found for “infrequency” of intercourse ( $\chi^2 = 5.76$ , df = 1, p = 0.016) and a trend towards significance for “vaginismus” ( $\chi^2 = 3.29$ , df = 1, p = 0.07). In addition, the association between a history of sexual abuse and sexual abstinence since receiving an HIV diagnosis was also investigated and was found to be significant ( $\chi^2 = 4.46$ , df = 1, p = 0.035).

The relation between GRISS subscales and disease variables was examined using  $\chi^2$  tests. A significant association was found between viral load and “non-sensuality” subscale of the GRISS ( $\chi^2 = 6.3$ , df = 2, p = 0.043). CD4 and viral load were not significantly associated with enjoyment of sexual activity since HIV diagnosis. Pearson correlations were used to investigate the association between GRISS subscale scores and time on treatment. A significant association was found for “avoidance” (p = 0.04) and a trend for “dissatisfaction” (p = 0.07).

## DISCUSSION

As in previous studies, the majority of women (72%) had resumed sexual activity after receiving their HIV diagnosis;

59% of women in this predominantly black African sample were in a relationship and half had been sexually active in the past month. Among the 67 women responding to an item about impact of HIV on sexual enjoyment, half stated that HIV had greatly impaired their enjoyment of sex or made it impossible. Not surprisingly, this was associated with more sexual difficulties (avoidance, infrequent sex, poor communication, and sexual dysfunction), as measured by the GRISS and also higher levels of depression. A proportion of women (21%) had not disclosed their HIV status to their sexual partner. Non-disclosure, poor communication, and sexual difficulties are likely to be inter-related and require further study.

Two thirds of sexually active women stated that they “always” or “usually” used condoms. A variety of reasons were endorsed for using them, the most frequent being to protect themselves from STIs. Reasons endorsed for *not* using condoms included partner refusal, both partners being HIV positive, reduced enjoyment for self and partner and desire to become pregnant.

High rates of past sexual abuse were found; however, there were no clear associations with relationship status and current sexual activity. This may reflect the context as some black African women had experienced rape during conflict in their country of origin. Sexual abstinence since diagnosis was significantly associated with a past history of sexual abuse, suggesting that HIV status alone is insufficient to explain why some women do not resume sexual activity.

Similar to one recent study,<sup>7</sup> taking antiretroviral therapy and length of time on treatment did not emerge as a significant factor effecting women’s sexual functioning. The number of women on PI regimens was unknown; therefore it was not possible to determine whether sexual difficulties were more prevalent in this subgroup.

The study has some limitations. Firstly, women who took part constituted a self selected sample and information about why women declined to participate would have been helpful. Secondly, there are no published sexual functioning questionnaires that have been standardised on African samples and it is not known how culturally appropriate these are. For example, GRISS subscales such as “infrequency” may be a culturally normative phenomenon and not necessarily a “dysfunction.” Furthermore, while the GRISS measures “infrequency” and “avoidance” of sex it does not specifically measure low sexual desire. Since the latter has been found in previous studies to be a common sexual problem in women with HIV infection,<sup>2,3</sup> future work should consider using questionnaires that measure hypoactive sexual desire. The study allowed a “snapshot” of women’s current sexual relationships. It reveals little about how and in what way these aspects of women’s lives change over time, following diagnosis, or how they might alter in the future. The decision not to use an HIV negative control group limits a fuller understanding of the specific impact of HIV on sexual relationships and behaviour and the implications that can be drawn from the findings.

### Key messages

- A majority of women (72%) had resumed sexual activity after testing HIV positive
- More than half of the women stated that HIV had impaired their enjoyment of sex or made it impossible to have sex
- Over two thirds of sexually active women with HIV infection stated they “always” or “usually” used condoms
- High rates of past sexual abuse were found
- Psychosexual interventions aimed at addressing sexual and relationship concerns should be offered to women and their partners, where appropriate



The high prevalence of sexual difficulties, including abstinence, in this sample of HIV positive women suggests a need for routine screening of sexual and relationship difficulties in women living with HIV. In addition, the association between higher rates of psychological distress and sexual difficulties indicate the importance of screening for mental health concerns. Culturally sensitive psychosexual interventions aimed at addressing these concerns should be offered for women and their partners, where appropriate.

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## CONTRIBUTORS

All authors were involved in the design of the study and the semi-structured questionnaire and collection of questionnaires from clinic attendees; AK and SL recruited participants from the voluntary organisations; SL undertook the majority of the data analysis, with assistance from AK and JP; SL wrote the paper; JP provided comments on the final draft and wrote the key messages.

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## ECHO

### Options for HAART may be limited



Please visit the Sexually Transmitted Infections website [www.stijournal.com] for a link to the full text of this article.

A small, but growing, group of patients with HIV in the UK faces the prospect of running out of treatment options if new antiretroviral drugs do not become available soon, a multicentre cohort study has predicted. These drugs will need to have low toxicity and not be subject to cross resistance to existing ones.

The UK collaborative HIV cohort (CHIC) study compared immunological and viral status among patients who had ever had highly active antiretroviral treatment, patients exposed to the three main classes of antiretroviral drugs, and patients showing viral load failure with that treatment, in more than 16 500 HIV infected adults during 1996–2002.

Patients most at risk are thought to be among those exposed to the three main classes of antiretroviral drugs, comprising 38% of treated patients in 2002—namely, the quarter with viral load failure. Their proportion has been rising steadily, and the proportions with CD4 counts <200 cells/mm<sup>3</sup> and HIV RNA >2.7log<sub>10</sub> copies/ml were high. Overall, 62% of the entire cohort was exposed to any antiretroviral treatment. The percentage that had ever had treatment rose from 41% initially to 71% in 2002, and the proportion with CD4 <200 cells/mm<sup>3</sup> and HIV RNA >2.7log<sub>10</sub> copies/ml fell, indicating successful control.

Patients with viral load failure with three treatments may have some resistance to other drugs in the same class and high risk of future treatment failure. Successive treatments tend to produce shorter term immunological and viral control, so that patients who have worked through several regimens may eventually have no other options.

▲ Sabin CA, *et al*. *BMJ* 2005;**330**:695–698.